

# Iowa Prevention of Disabilities Policy Council

## 2012 Annual Report

100 Hawkins Drive  
277 Center for Disabilities and  
Development  
Iowa City, Iowa 52242

### **Executive Committee Chair**

Cheryll Jones, Bloomfield

### **Vice-Chair**

Maggie Tinsman, Bettendorf

### **Immediate Past Chairs**

Scott Lindgren, Solon

Chris Atchison, Iowa City

### **Citizen Members**

Susan Lerdal, Urbandale

Joan Bruhn, Sioux City

Beth Jones, Johnston

Claibourne Dungy, M.D.

Iowa City

Randy Horn, West Des

Moines

### **Legislative Members**

Sen. David Johnson,

Ocheyedan

Rep. Lisa Heddens, Ames

Sen. Pam Jochum, Dubuque

Rep. Dave Heaton,

Mt. Pleasant

### **Director**

Kay DeGarmo

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## *Disability in Iowa*

Iowans with a disability are those who are limited in their ability to participate in and contribute to society due to difficulty with mobility (getting around), performing personal care, communicating, learning, and/or working. The disability may have started anytime during the life span – before birth, at birth, during childhood or adulthood, or as the result of the aging process. The disability may affect one or more areas of their lives. It may be obvious or hidden. It may also be mild or severe.

Today in Iowa disability affects . . . .

- About 5.3% of children between the ages of 5 and 17 years
- Around 18% of non-institutionalized adults

The percentage of Iowans with a disability increases with age. The type of disability also varies by age. Among children with disabilities, more have a mental disability (nearly 80%) than a physical or sensory disability. Among adults with disabilities, almost 90% have some type of physical disability.

Iowans with a disability experience significant social disparities. An Iowa Department of Public Health survey documented the following:

Measure	Those with Disability	Those without Disability
Employment Rate (< 65 years)	47% employed; 53% unemployed	84% employed; 16% unemployed
Average Household Income	\$40,600	\$57,800
Poverty Rate	22.7%	8.6%

## Our mission

Recognizing that as much as 25% of disability could be prevented or greatly reduced, the Iowa General Assembly created the Prevention of Disabilities Policy Council in 1991 (Iowa Code 225B). The Council is responsible for facilitating policy development and coordinating multiple state agency and public-private activities to prevent disability and improve the health and independence of those with disabilities. It is charged with advising the Governor and the Iowa General Assembly about priorities and policies in preventing disability and secondary conditions. The Council's core mission is to improve lives, increase independence, and save money through prevention. It is the only Iowa Council with this primary role.

Specific Council responsibilities include:

- Foster the planning, implementation and evaluation of a coordinated prevention strategy across the state departments and regents institutions;
- Facilitate collaborative and complementary activities among the public, private, and volunteer sectors;
- Develop and recommend a system to measure the outcomes and assess the overall impact of the state's prevention of disabilities efforts;
- Encourage research into the causes and prevention of disabling conditions;
- Promote training in state-of-the-art prevention measures;
- Recommend priorities and policies for the prevention of disabilities to the Governor and General Assembly;
- Assist agencies in obtaining federal and private funding to plan and implement initiatives in prevention of disabilities and secondary conditions; and
- Seek and apply for federal and private grants to support the responsibilities of the Council and further the state's prevention of disabilities agenda.

## How we work

Unlike most governmental entities, the Council does not directly operate programs; instead it works across the state departments, regent's institutions, and the private sector to carry out its mission. The Council annually reviews the environment and selects priority areas on which to focus its work. The priority areas that are selected help guide Council member appointments and activities. By law, the Council's voting membership includes 3 people with expertise in Council priority areas, 3 providers of services in Council priority areas, and 3 individuals with disabilities or their family members who have an interest in the Council's priority areas. The Council also includes 4 non-voting legislative members—2 from the House and 2 from the Senate.

The Council meets six times a year by webinar or in person. This year, five regular business meetings were held in January, May, July, October and December 2012. The sixth meeting was conducted in conjunction with a Council-convened Summit to develop a state strategic plan for improving the health of Iowans with disabilities. The Summit was held in February 2012.

Highlights of 2012 Council activities are presented below in the three current priority areas.

### ***Preventing injuries that result in disability***

Injury remains the leading cause of disability for those between the ages of 4 and 44 years. It is also an important cause of disability among older Iowans. Recent research has brought to light a new source of disability that is preventable. Scientific evidence has now identified a link between some sports related injuries, particularly those resulting in concussion, and life-long disability.

The Council has . . . .

- Received briefings about the public health effects of sports related injuries and reviewed recommendations about developing and implementing state-of-the-science prevention measures.
- Reached out to private and public organizations to promote implementation of measures that have been proven to increase safety and prevent disabilities, e.g.,
  - training coaches to identify potential concussions, and
  - promoting the use of helmets.
- Started working with the Iowa Fall Prevention Coalition, a group of organizations representing public health, aging services, healthcare, and physical exercise promotion who wish to advance awareness about falls in Iowa and promote strategies to prevent them.

### ***Promoting optimal child health and development***

New scientific evidence about early brain development has highlighted the importance of addressing childhood development, including social-emotional development, in the early years in order to avoid disability. Recent research has also brought to light significant unaddressed issues with the social-emotional health of teenagers.

The Council has . . . .

- Served in an advisory capacity to the Iowa Medicaid EPSDT *Care for Kids* Program to:
  - monitor EPSDT program outcomes,
  - identify opportunities for effective preventive activities,

- implement the Assuring Better Child Health and Development (ABCD) recommendations to Medicaid, and
- further develop an integrated, coordinated approach to screening and services for at-risk children and families.
- Served on the Iowa EPSDT *Care for Kids* Newsletter Board to identify issues and resources to address primary health care for children with and/or at risk for disabilities. The newsletter is published three times a year and reaches over 6,000 Iowa primary health care providers. This year, the newsletter addressed such topics as:
  - Sports related concussions
  - Health maintenance recommendations
  - ATV safety
  - Medicaid quality recommendations
  - Healthy adolescent health

### *Improving the health and wellness of Iowans with disabilities by increasing access and participation*

Attaining and maintaining good health is critical for people with disabilities to secure the freedom to learn, work, and fully engage with their families and communities. Iowa data show that people with disabilities face many health disparities that place them at risk of developing additional health conditions that will further limit their independence. They must be able to participate in everything a community has to offer, receive the services and supports they need to lead productive lives, and have access to the full array of health care and health promotion services.

The Council has . . . .

- Convened a statewide summit in February 2012 to lay the foundation for the development of Iowa's first ever *State Strategic Plan to Improve the Health of Iowans with Disabilities*.
- Collaborated with the Iowa Department of Public Health in the development of Iowa's Five Year Strategic Plan for Improving the Health of Iowans with Disabilities. The plan addresses four broad-based goals, including:
  - Improve access to health care and preventive health services for Iowans with disabilities
  - Build state public health capacity to address the health and wellness of Iowans with disabilities
  - Increase the participation of Iowans with disabilities in community services and activities that promote their health and well-being
  - Improve emergency preparedness and response for Iowans with disabilities
- Provided technical assistance to the Iowa Department of Public Health and UI Center for Disabilities and Development in the preparation of a successful competitive application to

the Centers for Disease Control and Prevention for a three-year grant to “Improve the Health of Iowans with Disabilities”.

- Served as the chief advisory body to the IDPH Disability and Health program and is currently advising that program regarding:
  - a statewide needs assessment,
  - creating a plan to sustain health promotion activities, and
  - building strong disability policy.
- Served as part of the Advisory Committee for the Iowa Department of Public Health Community Transformations Grant.
- Oversaw implementation of specific objectives related to disabilities in the Iowa Department of Public Health’s *Five Year Health Improvement Plan*.
- Provided information and recommendations to policy makers who are making decisions about implementation of the Affordable Care Act regarding essential health care benefits for Iowans with disabilities including but not limited to prescriptions, behavioral services, habilitative/rehabilitative care, and medically necessary equipment at affordable rates.
- Supported the development of programs and services that create a seamless system of care to transition youth with disabilities and chronic health conditions into adult health care.
- Began working with the Iowa Medicaid Enterprise, Child Health Specialty Clinics (Iowa’s Title V program for children with special health care needs), and the UI Center for Disabilities and Development to plan a statewide initiative to improve health care transitions for Iowa youth with disabilities.
- Proposed strategies for ensuring that all state agencies require their contractors to have plans in place to improve accessibility for Iowans with disabilities.
- Supported continuing implementation of Iowa’s Mental Health and Disability Redesign.

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*Improving lives, increasing independence, and saving money  
through prevention*

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December 2012

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Rep. Dave Heaton, Mt.  
Pleasant

## **Director**

Kay DeGarmo  
(319) 358-6499  
kay-degarmo@uiowa.edu

## **Our Mission**

Disability currently affects over 5.3% of Iowa children between the ages of 5 and 17 and 19% of adults. Recognizing that a significant amount of disability could be prevented or greatly reduced, the Iowa General Assembly created the Prevention of Disabilities Policy Council in 1991 (Iowa Code 225B). The Council is responsible for facilitating policy development and coordinating multiple state agency and public-private activities to prevent disability and improve the health and independence of those with disabilities. It is charged with advising the Governor and the Iowa General Assembly about priorities and policies in preventing disability and secondary conditions. The Council's core mission is to improve lives, increase independence, and save money through prevention. It is the only Iowa Council with this primary role.

Unlike most governmental entities, the Council does not directly operate programs; instead it works across the state departments, regent's institutions and the private sector to carry out its mission. The Council is currently working on the following priorities:

- **Preventing injuries that result in disability**
- **Improving the health and wellness of Iowans with disabilities by increasing access to community services and health care**
- **Promoting optimal child health and development**

## **Preventing injuries that result in disability**

Injury remains the leading cause of disability for those between the ages of 4 and 44 years. New scientific evidence has identified a link between some sports related injuries, particularly those resulting in concussion, and life-long disability. The Council has reviewed the science and the public health effects of these injuries and is working with private and public organizations to promote implementation of measures that have been proven to increase safety and prevent disabilities (e.g., training coaches to identify potential concussions and promoting the use of helmets).

# IOWA PREVENTION OF DISABILITIES POLICY COUNCIL

*Improving Lives, Increasing Independence, and Saving Money through Prevention*

## 2013 LEGISLATIVE RECOMMENDATIONS

### PRIORITY 1: PREVENTING INJURIES THAT RESULT IN DISABILITY

- Support the expansion of the 2011 Iowa Youth Sports and Brain Injury law to extend coverage to young athletes of all ages in all organized venues across the state.
- Support passage of a Universal Helmet Law for persons using bicycles and motorcycles.

### PRIORITY 2: FACILITATING THE INCLUSION, INDEPENDENCE, AND PRODUCTIVITY OF PEOPLE WITH DISABILITIES

- **Continue to implement Iowa's Mental Health and Disability Redesign (SF 2315).**
  - Support providing the funds necessary for one-time county funding to implement sustainability plans in FY 2013. Support funding in FY 2014 and future fiscal years for per capita Property Tax Equalization to permit impacted counties to continue to provide vital non-Medicaid services.
  - Support the continuation of efforts to stabilize and modify the definitions for available core services and "core plus" services, and to expand the populations served.
  - Identify and leverage new revenue sources, such as those made available through federal health care reform legislation, to expand effective community-based services and systems of care.
- **Ensure that community services for all Iowans are fully accessible for Iowans with disabilities.**
  - Request inclusion in the FY 2014 Appropriations Standings Bill of the requirement that State of Iowa departments implement ADA compliance requirements within agencies and with all community contractors.
  - Support the development of a public-private initiative to improve access to essential community services for people with disabilities. This initiative should include accessibility surveys, technical assistance, and development of a statewide website to act as a clearinghouse for counties, cities, and other governmental subdivisions regarding accessibility, policies, and low-cost access solutions.

### PRIORITY 3: ADDRESSING ACCESS TO HEALTH CARE FOR PEOPLE WITH DISABILITIES

- Assure that health care provided to Iowans through any public or private plan offers the essential benefits necessary for individuals with disabilities, including but not limited to prescriptions, behavioral services, habilitative/rehabilitative care, and medically necessary equipment at affordable rates. This should include the Health Benefits Exchange, Accountable Care Organizations, and Medical/Health Home programs.
- Promote strategies that improve the scope and quality of patient-centered primary care services designed to reduce the development of "secondary conditions" including adverse medication effects.
- Support the development of programs and services that create a seamless system of care to transition youth with disabilities and chronic health conditions into adult health care.

### PRIORITY 4: PROMOTING OPTIMAL CHILD HEALTH AND DEVELOPMENT

- **Lay the foundation for sustainable, policy-supported systemic improvements in the way young children and families at risk are identified, referred, linked to services, and followed. Support programs and activities that:**
  - Provide training and incentives to community health care providers to offer the full array of elements needed to perform care coordination at the level expected of a Medical/Health Home.
  - Create and maintain effective linkages between primary health care providers and other community-based service providers.
  - Develop a systematic approach to match child/family needs with the most appropriate care coordination resource.
  - Develop a mechanism to track children and families at risk to assure that they are not lost to follow-up and that they receive the services needed to prevent serious disabilities.